

# News on Developmental Disabilities



## Area Connection



March 2004

Area Board 6, 2529 W. March Lane, Ste. 105, Stockton, CA 95207 (209) 473-6930; info@areaboard6.org; www.areaboard6.ca.gov

**Area Connection** is a publication of the Area 6 Developmental Disabilities Board. Area boards are established under state law as a program of the **State Council on Developmental Disabilities**. They protect and advocate the rights of persons with developmental disabilities, and conduct local advocacy, capacity building and systemic change activities. Area Board 6 serves Amador, Calaveras, San Joaquin, Stanislaus and Tuolumne counties.

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## In-Home Supportive Services Program



The In-Home Supportive Services program, IHSS, provides services for low-income aged, blind, and disabled persons that enable them to live safely in their own homes. The IHSS program has two parts: 1. The original and smaller IHSS program called the "residual program", funded only with state funds; and, 2. The larger Personal Care Services Program (PCSP), which is funded with federal **and** state funds - 50% federal funds, and 50% state funds.

To save money for the State of California, the Governor has proposed a number of cuts to the IHSS program.

The largest cut would be made by eliminating California's original IHSS program, the "residual program",

for a savings of \$366 million in 2004-05. This action would affect 75,000 people who now receive services from the "residual program". The 75,000 individuals who make up the caseload of the "residual program" are for the most part, either, (1) individuals who receive **only** domestic services, such as cleaning and meal preparation; (2) individuals whose parent or spouse is their provider; or, (3) individuals who receive protective supervision. The Governor's Budget assumes that 18,000 of the 75,000 recipients in the "residual program" will choose another provider who is **not** a relative or a spouse, and that the remaining 57,000 individuals will become ineligible for IHSS services thereby achieving projected savings for the State of \$366 million.

*Cont. on page 5*

## Parental Share of Cost Plan

As directed by the Legislature, the Department of Developmental Services (DDS) developed a draft proposal that presents two options for a system of fees, or co-payments, to be charged against parents of children ages 3 through 17 who live in the parent's home, receive services from a regional center, and are not eligible for Medi-Cal.

### Option One

Under this option, the State would administer the program. It would have two parts: An enrollment fee; and, a co-payment assessment.



The enrollment fee would be a flat annual fee set by DDS for each family. There would be one fee per family no matter the

*Cont. on page 6*

## Proposed Purchase of Service Standards

The proposed Purchase of Service Standards for regional centers may soon become law. These draft proposals from DDS seek to establish rules that will standardize case management, plan development, service selection and fiscal administration across the state. In some cases, if adopted, they may drastically alter the services and supports you can expect from your local regional center.

The Standards are broken down into several categories. Beginning with **General Standards**, the language sets a clear tone of careful scrutiny for all expenditures. Only those services that alleviate a developmental disability, habilitate an individual, or seek to achieve or maintain independence are eligible for funding. Pursuing generic resources for primary funding whenever possible is emphasized. Procedures for securing private family medical insurance are established. Service and equipment requirements are standardized. And an annual accounting of regional center funded services shall be provided to consumers or families.

One provision that may be very controversial is the requirement that the least costly vendor who is able to meet the consumer's needs shall be selected. Reducing the focus on quality of service in the interest of cost may unduly pres-

sure service coordinators to select services that only marginally meet the consumer's needs. This may, in turn, create more stress in other life areas, which could actually increase costs overall.



Under **Prohibitions**, a provision that solidifies the current policies of many regional centers acquires the weight of law. "Experimental treatments, therapeutic services, or devices that have not been clinically determined or scientifically proven to be effective..." are prohibited. This means music therapy, equestrian therapy, and several emerging treatments that may have demonstrated remarkable results, but do not have the support of scientific proof (which usually takes years to establish) will no longer be funded by regional centers. Some middle ground should be provided here to allow for funding of those therapies that have demonstrated their benefit to consumers through structured trials, but have not yet gained the standing of scientific proof, especially when scientifically established therapies have already failed. There is also the question of what happens when disagreement occurs among the vari-

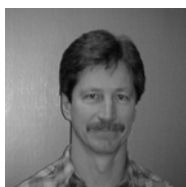
ous regional centers regarding proven therapies.

The section on **Adult Day Program Services** has an immediate impact on young adults. Because regional centers may only purchase day program services for consumers who are no longer eligible for publicly-funded education, several people between the ages of 18 and 22, who have already received a high school diploma or certificate of completion, will have to wait until after their twenty-second birthday to receive adult services. Those who do not wish to return to school and repeat their classes, which they may already have mastered, will have no choice but to sit home and wait.

Also in this section is the provision that regional centers must consider the combined cost of transportation *and* day programming, then select the least costly option. For some, this requirement may be a benefit that brings them closer to their home community. For others, it may disrupt long established supports, separate them from friends, and unduly restrict their access to the community.

Proposed standards for **Transportation** will bring changes to many current services. Funding for transportation to any appointment will be disallowed, unless the appointment is related to a developmental disability.

*Cont. on page 4*



Paul L.  
Symmonds

## The Advocate's Voice

Parents representing their children in IEP meetings sometimes bump heads with school officials over Designated Instructional Services (DIS). Known in federal law as "related services," and in California as Designated Instructional Services, these are any services that are necessary to help a student benefit from his special education program. A better understanding of the regulations and requirements related to DIS will often minimize conflicts and help to create much better Individualized Education Plans.

Schools are only required to provide services that are necessary in order for the student to make *meaningful progress toward meeting IEP goals and objectives*. This may create a conflict among the IEP team. The school's idea of meaningful progress may differ from the parents' interpretation of that phrase. Also, parents are sometimes frustrated when a child truly needs a service, but the school states that the service is not necessary to help the child benefit from his education. Before you draw your battle lines and march toward a fair hearing, be sure to consider a few key points.

First, remember that the IEP document is a contract between the child and the school. Once the IEP team establishes the child's current educational

and developmental levels, the team must then decide 1) what educational goals are most appropriate, 2) what services are necessary to achieve those goals, and 3) who will provide those services. Any DIS therapy or service that is determined to be necessary should be written into the IEP document, along with specific information on the frequency, location and duration of the service to be provided. Conflicts often arise when parents feel their child is not receiving the level of service required. However, if the level of service is clearly written into the IEP document (along with the goals and objectives of that service), then no change can be made to that service until the IEP team convenes and approves the change. You can also avoid potential gaps in service by writing into the IEP document what will happen if a DIS provider is absent or unable to perform the service as described.



When parents believe their child is not progressing as he should, they may request additional, or more frequent services. If the school responds that the child is currently receiving an appropriate level of service, and making meaningful progress toward his

educational goals, it would be advisable to review the IEP goals and objectives to make certain that they are appropriate to the needs and potential of the child. If the goals seem inappropriate, they should be restructured in a manner that allows the child to advance toward his potential. If there is strong disagreement over learning potential, parents may want to meet with the school psychologist for an explanation of the child's assessment results and a discussion of reasonable expectations. Outside assessments can sometimes be helpful, so long as the person providing the assessment understands how the information he provides relates to special education laws and services. Sometimes parents can negotiate trial periods for specialized services. This allows the IEP team to gather good information on whether the service is educationally appropriate without compelling the school to commit to a long-term service it may view as unnecessary.

The *Special Education Rights and Responsibilities* book published by *The Community Alliance for Special Education and Protection and Advocacy, Inc.* devotes an entire chapter to Designated Instructional Services, for good reason. If your child requires the services of your local special education program, I urge you to obtain and acquaint yourself with this book.

**POS**—*Cont. from page 2*

Mobility training will be mandatory for anyone deemed capable of using public transportation. Consumers who work full-time will not be allowed transportation services. While these changes make sense, some allowance should be made for certain emergency or chronic conditions. And the required use of public transportation must be sensitive to mental health or vulnerability issues that may limit a consumer's regular access.

**Respite** has not been eliminated as a funded service, but it has been limited. No more than 21 days per fiscal year of out-of-home respite may be authorized. No more than 72 hours per quarter of in-home respite will be allowed. And, unused days or hours may not be carried over into the following period. This will result in significant cuts in current services, and create several hardships for families who have come to rely on respite.

The most significant restriction on **Day Care Services** seems to be the provision that regional centers may fund day care only when parents are engaged in full-time work, training or school. Part-timers need not apply.

**Early Intervention Services** (birth to age three) are still a priority, as they should be. However, clear instruction is given to regional centers to pursue all possible

funding sources, including the family's private insurance. While the policy is fiscally sound, and has already been implemented in many cases, it may create undue friction between families and regional centers as the regional centers, unavoidably, become more involved in the families' financial affairs.



The remaining categories of assistive technology/environmental adaptations, behavioral services, social/recreational activities, supported living services, specialized medical/dental services, therapies and supplemental services do contain new restrictions, but they are less severe, and still comply with federal requirements. Social/recreation hours have been limited to a maximum of 10 hours per week (or 130 hrs/qtr), but Valley Mountain Regional Center already caps social/recreation hours at 60 hours per quarter, so few are likely to be affected.

Overall, the proposed standards are an ambitious attempt to fairly address the financial constraints facing us all. Many services are contingent upon clear assessment results that indicate their need. This provides accountability as well as a basis for evaluation of

future services, though it will also cause some service delays. As a framework that twenty-one separate regional centers can use to reduce or eliminate current disparities in services and supports, it may prove to be a valuable tool. However, the fundamental shift from IPP driven services, based on need, to the least costly alternative available has the potential for harm to the quality of every consumer's life, and may threaten the core principles of the Lanterman Act.

We don't really know what impact these reductions will have in other areas, or whether other costs will rise in response. A careful look by everyone involved directly or indirectly with people who have developmental disabilities is required. You can view the [Purchase of Service Standards](#) draft, as well as the draft of the [Family Cost Participation Assessment Program](#), on the DDS website ([www.dds.ca.gov/0405proposals](http://www.dds.ca.gov/0405proposals)). Comments on those drafts can be directed to your local state representative, or to Wesley Chesbro, Chairman of the Select Committee on Developmental Disabilities and Mental Health.

**IHSS—Cont. from page 1**

Another cut would reduce the amount California pays providers to the state minimum wage of \$6.75. Currently, the state pays \$9.50 per hour of provider wages plus 60 cents per hour worked for health benefits. This action would save the state \$98 million in 2004-05.



A third cut would eliminate the requirement that counties have an “employer of record.” According to the Legislative Analyst, this action effectively removes the requirement that counties operate public authorities and have advisory committees. (LAO, Feb. '04, Analysis of the 2004-05 Budget Bill).

A fourth cut would be made by making changes to the need assessment process used to decide how many hours of service individuals will receive.

The Legislative Analyst's Office is on record as saying that the proposals to eliminate the residual program and reduce the state's payment of provider wages to minimum wage results in a potential hardship for low-income Californians who receive IHSS. The LAO recommends the Legislature, “...consider each aspect of the proposal on a case by case

basis, assessing both its impact on recipients and the estimated savings.”

Sources for more information on this topic include the following: Legislative Analyst's Office, [www.lao.ca.gov](http://www.lao.ca.gov); Protection and Advocacy Inc. at [www.pai-ca.org](http://www.pai-ca.org); California Budget Project at [www.cbp.org](http://www.cbp.org); The Arc of California at [www.arccalifornia.org](http://www.arccalifornia.org); and, California Alliance for Inclusive Communities, [www.caic.org](http://www.caic.org).

The Area 6 Board meeting on March 30<sup>th</sup> will feature a presentation on the topic with George McHugh, Executive Director of San Joaquin's Public Authority. See the back page of the newsletter for details.

## IDEA Reauthorization

The legislative process reauthorizing the federal law, Individuals with Disabilities Education Act (IDEA) has been proceeding in Congress with bills in the House and in the Senate. While advocates regard S.1248 more favorably than the House version, many still believe S.1248 is unacceptable.

To communicate opposition to the bill to Senators, several organizations have organized a National Call in Day. For more information go to TASH website at [www.tash.org](http://www.tash.org), or, Our Children Left Behind site, [www.ourchildrenleftbehind.com](http://www.ourchildrenleftbehind.com).



**Enter the –**

**Area Board 6**

**Website at:**

**[www.areaboard6.ca.gov](http://www.areaboard6.ca.gov)**

**for the latest information on  
the budget situation  
affecting people with  
developmental disabilities!**

### Parental Share....-Cont. from page 1

number of regional center consumers in the family. The enrollment fee would be collected to offset the cost of implementing the program.

The co-payment assessment, which would be set each year, would be based on the cost of services used in the previous year and the annual gross income of the family. To be assessed the co-payment, a family's annual gross income would have to be above a pre-determined percentage of the Federal Poverty Level (FPL) as adjusted for family size.

If a family neglected or refused to pay, their child, or children, would not be denied regional center services, however, the DDS would "vigorously pursue" collections, including through the courts if necessary.

DDS' report outlines the elements needed to implement and administer the program under this option along with the advantages and disadvantages of the option.

**Comment:** DDS finds it an "advantage" if family's lower their expectations and ask for less; as per the following statement in the report: "In future years the schedule could assist in containing POS costs as families assess their need, taking into consideration their financial responsibility." But, DDS finds it a "disadvantage" if a family decides to ask for nothing and discontinue the

use of regional center services. In other words, the program is expected to have a dampening effect on demand for services.

#### Option Two

DDS refers to the program in this option as the Family Cost Participation Assessment Program. The program under this option would be administered by the regional center.

The amount of the "family cost participation" would be established by the regional center based on a schedule set by DDS linked to income and family factors. It would occur during the authorization of purchased services at the regional center. It appears that the cost of various services would be calculated at this time, along with the calculation of the amount the family would pay and the difference that regional center would pay. Families would pay their portion of the service cost directly to the service provider agency.



The family's gross income would be determined annually, or sooner if there was a significant change in the family's circumstances. There is no enrollment fee with this option.

DDS states that advocates argued against a regional center administered

program, expressing strong concerns about confidentiality and conflict of interest. DDS replies to the concerns by citing state and federal law on confidentiality and the consequences for breach of the law. On conflict of interest, DDS says that, "...the duties of the person or team that prepares the IPP (will be separated from) the person that will set the Parental Cost Participation Assessment."

To read the complete proposal see the DDS website, [www.dds.ca.gov](http://www.dds.ca.gov).

### Websites

Modifying materials  
for people  
with cognitive disabilities:  
[www.ncddr.org/du/researchexchange/v08n03](http://www.ncddr.org/du/researchexchange/v08n03)

\* \* \* \* \*

Keep track of what is  
going on in Congress and  
your State legislators:  
<http://capwiz.com/thearc/home/>

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Disability Benefits:  
[www.disabilitybenefits101.org](http://www.disabilitybenefits101.org)

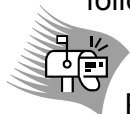
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[www.searchdisabilities.com](http://www.searchdisabilities.com)  
Provides current information  
on medical research,  
assistive technology, and  
independent living for people  
with disabilities, their  
supporters  
and caregivers.

## Upcoming Events

### Special Education Rights Workshops

There is **no cost** to attend the following workshops but reservations are **required**.



Please mail, phone, or e-mail your reservation to the Area 6 Board Office.



**April 1, 2004**

6:00 pm to 8:30 pm  
Tuolumne General Hospital  
101 E. Hospital Road  
Sonora

**May 6, 2004**

6:00 pm to 7:45 pm  
San Andreas/Calaveras Library  
891 Mt. Ranch Road  
San Andreas

### Disability Capitol Action Day

Californians with Disabilities of All Ages and Their Supporters  
Thursday, May 20, 2004  
RALLY at 11:00 am  
State Capitol, Sacramento  
West Steps

8:00-10:30 & 12:00-5:00

APPOINTMENTS with YOUR Legislators!

For more information  
Contact Teresa Favuzzi  
At 1-800-390-2699  
TDD 1-800-900-0706

[www.cfild.org](http://www.cfild.org)

E-mail: [teresa@cfild.org](mailto:teresa@cfild.org)



### Parental Rights and Advocacy in Special Education

**March 30, 2004**

Presenter: Ann Cirimele  
Family Resource Network  
Stockton

For more information,  
call FRN at 800-847-3030

### Moving On...

### Transitioning from the Early Start Program

**April 21, 2004**

Presenter: Ann Cirimele  
Family Resource Network  
Stockton

For more information,  
call FRN at 800-847-3030

### Parental Rights & Advocacy:

### Tips for Meeting the Needs of a Child in Special Education

**April 24, 2004**

Presenter: Ann Cirimele,  
Family Resource Network,  
Family Resource &  
Referral Center  
509 W. Weber Ave., Ste. 103  
Stockton

For more information,  
call Megan Burnham  
At 209-461-2614

### Autism

### Collaborative Forum

**Saturday, April 3, 2004**

Keynote Speakers:

G.David Demetral, Ph.D. LCSW  
& Robin L. Hansen, M.D.

San Joaquin County  
Office of Education  
2707 Transworld Drive  
Stockton

Call 209-468-9283  
for more info

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### CHOICES Institute Annual Conference

### Advocacy,

### Arts & You!!!

**Friday, April 23, 2004**

San Joaquin County  
Office of Education  
2707 Transworld Drive  
Stockton

Call 948-8011 for info!

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### Walking for Prader-Willi Syndrome

**Saturday, May 1, 2004**

Sign In: 10:30 am

Walk Time: 11:00 am

Join us for a "Picnic in the Park" following the Walk.

Bring your own lunch -

Beverages provided

Entertainment will include a band and Fun for the kids!

Call 800-400-9994 for info

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## Join us at the Area Board Meeting!

**Tuesday, March 30, 2004, 6:00 pm  
Kaiser Permanente  
7373 West Lane,  
2nd Floor, Conference Room A & B  
Stockton**

The Area 6 Board meeting will include presentations and discussion on several items that are of particular importance to people with developmental disabilities and their families. The items are as follows:

- 1. Governor's Draft State Budget Proposal to Make Cuts in the IHSS Program.**
- 2. Draft Purchase of Service Standards, and Proposed Trailer Bill Language.**
- 3. Proposed Family Cost Participation**

George McHugh, Executive Director, San Joaquin Public Authority, will speak on the effects of the IHSS proposal on consumers in San Joaquin County.

Other agenda items include reports on-

- Area Board 6 Executive Committee
- Life Quality Assessment Report
- Self-Advocacy Council VI
- State Council on Developmental Disabilities



### **State of California**

State Council on Developmental Disabilities  
Area Board 6  
2529 W. March Lane, Ste. 105  
Stockton, CA 95207

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